What does a positive new-born screen mean?

A change in your baby's DNA does not mean that your child has cystic fibrosis. In order to determine if your child has CF, a sweat test must be performed. Your doctor will let you know if a sweat test is needed and which one of the nationally-accredited CF laboratories you should use.

Indiana State Department of Health

Resources

For more information about cystic fibrosis

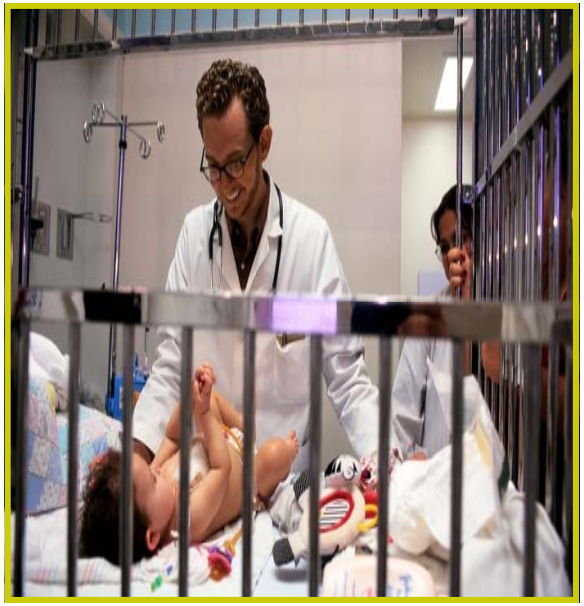
Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, MD 20814
(800) FIGHT-CF (800-244-4823)
www.cff.org

Indiana State Department of Health
Constance Burrus
Cystic Fibrosis Program Coordinator
2 North Meridian Street, 7B
Indianapolis, IN 46204
(317) 233-1292
http://www.in.gov/isdh/programs/nbs

Indiana State Department of Health Newborn Screening Program
(888) 815-0006

Indiana State Department of Health Family Helpline
(800) 433-0746

Cystic Fibrosis



What you should know

Indiana State Department of Health
2N Meridian St, 7B
Indianapolis, In 46204

Tel 888-815-0006
Helpline 800-433-0746
Http://wwwl.in.gov/isdh

What is Cystic Fibrosis?

Cystic fibrosis (CF) is a **life-long** illness that is usually diagnosed within the first few years of life. Patients with CF have problems with **breathing** and **digestion**. Some males with CF will be **infertile** (unable to have their own biological children). Cystic fibrosis does not affect a person's appearance or intelligence. More than 30,000 children and young adults in the United States currently have CF.

Ask your doctor if you should get genetic counseling

What causes cystic fibrosis?

Cystic fibrosis is a **genetic condition**. **Genes** are packages of information that tell your body how to grow and develop. Genes always come in pairs. Everyone has two copies of each gene, including the gene that can cause CF. One copy comes from your mother and the other copy comes from your father.

Some genes do not work properly because a change is present in that gene. If a person has a change in **both copies** of the gene for CF, he or she will develop cystic fibrosis. If a person has **one** changed copy of a CF gene, the person is a **carrier** for CF. Carriers will not develop CF, but they have a higher chance to have a child with CF.

Indiana State Department of Health

2N Meridian St., 8C
Indianapolis, In. 46202

How is CF treated?

Although there is no cure for CF, good medical care does make a difference. There is a wide range of treatments available. These may include antibiotics and dietary vitamins. If your child has cystic fibrosis, your child's doctor (s) will talk about treatments with you.

When is testing done for CF?

The newborn screening lab will use the same blood sample that is collected for the newborn test (or heelstick). The screen for cystic fibrosis is done in two parts:

- The lab will measure the level of a protein called **immunoreactive trypsinogen** (IRT) in the blood.
- A **DNA test** will be done **only** for children who have a high level of IRT in their blood. In Indiana, the DNA test will look for 46 of the most common gene changes that cause CF.